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ABSTRACT

The Parent Leadership Program team that created and facilitated a Local Liaison Learning Group between September 1998 and November 1999 gathered in mid-January 2000 to discuss what they had learned. The Learning Group was thought of by the Parent Leadership Program team as an applied research setting for investigating the conditions that support or undermine change in families of children with disabilities and their communities. The compilation of a learning history, designed to capture Learning Group participants' views of their local projects at four points in the project years, describes a process intended to support change and intervention which mostly did not occur, because of the inability of project teams to overcome the barriers to taking any sustained and broad-based action to influence their communities. The learning process did, however, contain important lessons for people concerned about improving family support and creating effective parent-professional partnerships. Lessons were learned also about the difficulty of acting creatively outside the boundaries of established roles and practices. (CR)

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Learning About Community Support for the Families of Children with Disabilities

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Reflections on the Local Liaison Learning Group

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Parent Leadership Program

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Perspective

The Parent Leadership Program (PLP) team that created and facilitated the Local Liaison Learning Group (Learning Group) between September 1998 and November 1999 gathered in mid-January 2000 to think about what they have learned from their experience.[1] The team thinks of the Learning Group as a sort of applied research setting for investigating the conditions for changes that will make an important difference to families and their communities. This understanding led them to invest in the compilation of a learning history, which captures Learning Group participants' views of their local projects at four points in the project year.[2] It also led them to invite John O'Brien to spend two days listening to their account of their work and to write these reflections, which express his thoughts after listening to their conversation and reading the project's records.

These reflections arise from a learning process designed to support changes that mostly did not happen. Many participants describe important results but, judged in terms of its intended outcomes –to significantly increase the natural support available to children with disabilities and their families in twelve counties– both the learning process and the larger change initiative its sponsors intended were mostly unsuccessful. This disappointing outcome does not result so much from the failure of projects that were implemented as from the inability of project teams to overcome the barriers to taking any sustained and broad-based action to influence their communities. It would be a mistake to draw conclusions about communities' ability or willingness to offer natural supports based on what happened in these projects: by and large, communities were not asked.

This learning process does hold important lessons for people concerned about improving family support and creating effective parent-professional partnerships. They are lessons about the difficulty of acting creatively outside the boundaries of established roles, practices, and mental models. The experience of participants in this learning group makes it clear that it is easier to talk about "thinking outside the box" than it is to do things that challenges the boundaries of existing boxes; it is easier to talk about partnership than it is to act as partners; it is easier to talk about increasing the

[1] A core team of three – Bryn Fortune, Sharon Dietrich, and Joan Blough– manage PLP activities. For the Learning Group, Nancy Peeler joined the core team as the learning historian. In this report, PLP team means the four person team that facilitated the Learning Group.

[2] A detailed description of the process and a record of the learning histories will be found in Parent Leadership Program (1999), *Local Liaison Learning Group Final Report: Parts 1 and 2.* Lansing, MI: The Arc Michigan. (Contact: Sharon Dietrich at 1.800.292.7851, extension 115.)

availability of natural support than it is to sustain the work that will create reciprocal relationships between children and families with disabilities and ordinary community members.

It is fashionable to look to the business world to set the pace for human services. Perhaps the experience of the alliance of business people, organizational consultants, and researchers gathered under the leadership of MIT's Peter Senge and his colleagues can provide a benchmark. Introducing the most recent volume arising from more than 10 years of hard and (by human service standards) extremely well funded collaborative work, Senge writes,[3]

> *Most change initiatives fail. Two independent studies in the early 1990's, one published by Arthur D. Little and one by McKinsey & Co., found that out of the hundreds of corporate Totality Quality Management (TQM) programs studied, about two thirds "grind to a halt because of their failure to produce hoped for results." Re-engineering has fared no better: a number of article, including some by re-engineering's founders, place the failure rate somewhere around 70 percent. Harvard's John Kotter, in a study of one hundred top management-driven "corporate transformation" efforts, concluded that more than half did not survive the initial phases. He found a few that were "very successful" and a few that were "utter failures." The vast majority lay, "...somewhere in between, with a distinct tilt toward the lower end of the scale." Clearly, businesses do not have a very good track record in sustaining change....*
>
> *Our core premise is that the sources of these problems cannot be remedied by more expert advice, better consultants, or more committed managers. The sources lie in our most basic ways of thinking. If these do not change, any new "input" will end up producing the same fundamentally unproductive types of actions.* [Pages 5-6]

Please read these reflections in terms of the importance Senge attaches to our understanding and learning to develop our most basic ways of thinking. By reflecting on a detailed review of their work with the learning group,

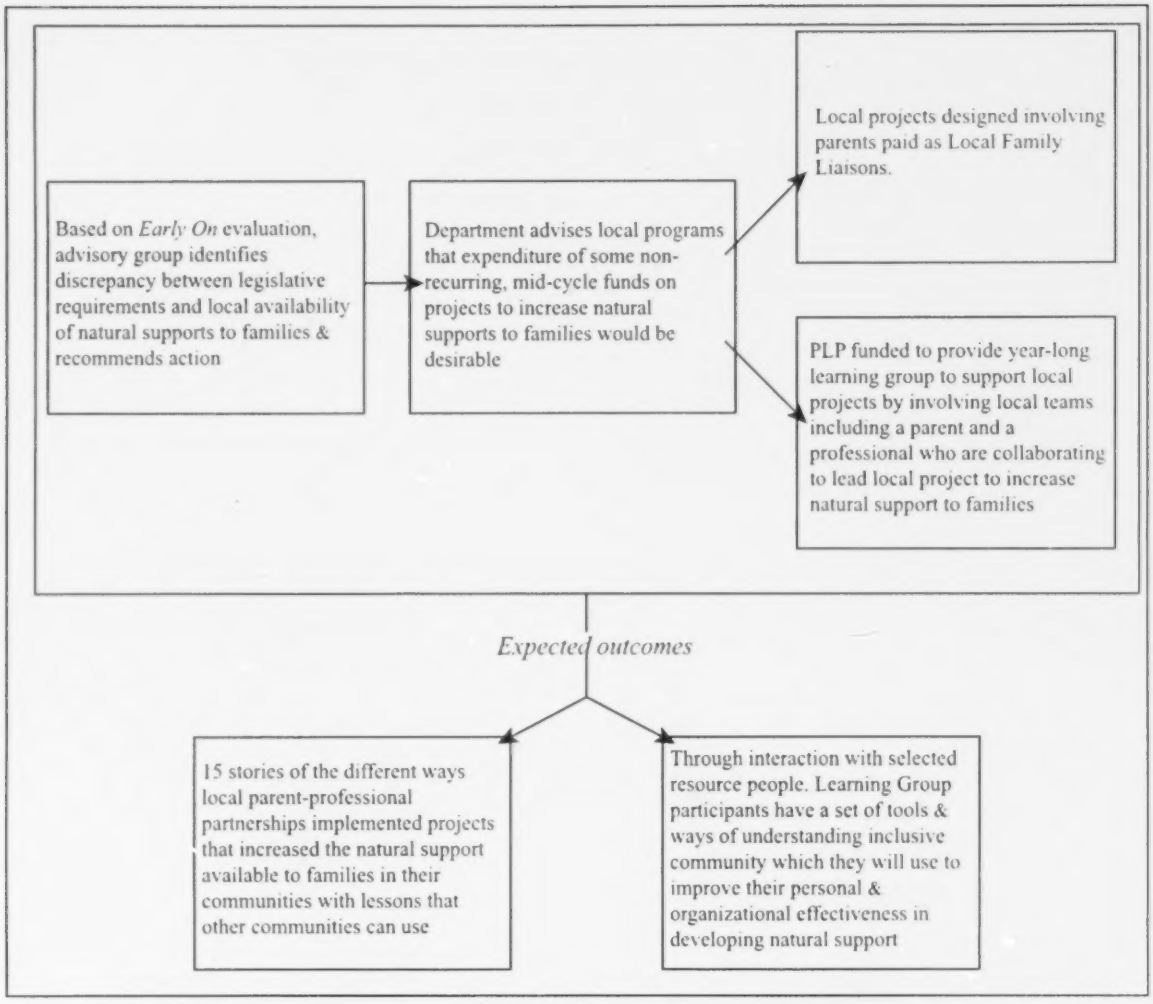
[3] Senge P., et al. (1999). *The dance of change: The challenges of sustaining momentum in learning organizations*. New York: Doubleday Currency. References to the studies cited in the quotation are in the original at page 6.

the PLP team made more of their own thinking explicit and traced some of its effects on their work. In doing so, they have further clarified both the meaning of family support and the process of significant change.

Resources on Learning Histories

Those interested in the kind of reflection supported by learning histories will want to consult George Roth and Art Kleiner (2000) *Car launch: The human side of managing change*. New York: Oxford University Press. This book presents the learning history of a set of interventions aimed at improving the work of a team charged with product development, an effort that succeeded at the level of team performance but failed to have the intended influence on the company that sponsored the interventions.

A guide to learning history resources can be found on the internet at www.sol-ne.org


Based on *Early On* evaluation, advisory group identifies discrepancy between legislative requirements and local availability of natural supports to families & recommends action
Department advises local programs that expenditure of some non-recurring, mid-cycle funds on projects to increase natural supports to families would be desirable
Local projects designed involving parents paid as Local Family Liaisons.
PLP funded to provide year-long learning group to support local projects by involving local teams including a parent and a professional who are collaborating to lead local project to increase natural support to families
Expected outcomes
15 stories of the different ways local parent-professional partnerships implemented projects that increased the natural support available to families in their communities with lessons that other communities can use
Through interaction with selected resource people. Learning Group participants have a set of tools & ways of understanding inclusive community which they will use to improve their personal & organizational effectiveness in developing natural support

Actual results

- Those who stayed involved in the Learning Group report high satisfaction with the sessions, important personal support from their involvement, & significant learning. Participants report using some of the tools back home
- 4 of 15 local teams never formed (though one person from each participated in a re-formed team); 2 teams withdrew from the Learning Group
- While most teams reported some local activity connected to their projects, most projects encountered many barriers in local systems & none of the projects were implemented as proposed
- Some participants reported an increase in the natural support available to their own families
- PLP made significant gains in team ability to facilitate learning through dialogue and reflection & in understanding of parent-professional partnership & the relationship between service system & natural support

Surfacing and Revising Assumptions

Both the Local Liaison Projects and the Learning Group resulted from a typical administrative process, which is outlined in the diagram on the facing page. Evaluation data signals a discrepancy between legislative intent and local performance, an advisory group assigns priority to addressing the discrepancy, available funds are directed toward both a set of local projects and a structure of training and technical assistance to guide them, expected outcomes are specified. Multiple repetitions of this linear process at different scales and levels of elaboration constitute one of the main administrative instruments available to federal and state systems that want to influence the behavior of local systems that they cannot directly control.

For the PLP team, the Learning Group was more than a routine project. Team members have a strong personal and professional stake in the issues of parent-professional partnership, family support, and the development of natural support. Feedback from their six years of training parents gave them confidence that they had an important contribution to make to professionals, and especially to parent-professional teams. Their own team development activities had involved them with a number of resource people they wanted to share with a wider audience in Michigan. Reflection on their work in the context of a workshop that gave them time to explore a variety of perspectives on organization and leadership had given them images of the sort of work they wanted to do. One image with considerable appeal to the team portrays their work as gardening: discovering how to provide the conditions to nurture what wants grow naturally and sustainably in the lives of people, families, and communities. The Learning Group offered what they hoped would be fertile ground for their investigations.

The learning history process gave the PLP team early notice of a significant disconnection between expected outcomes and project team activities. This disconfirming news faced the team with three options:

- Act as the "project police" by pushing local teams to be more specific about timelines and monitoring their performance. Some Learning Group participants seemed to expect the team to play this role. Some par-

ticipants were anxious about being dropped from the group because their local project was not developing as planned. Some participants were angry that the PLP team was not exerting pressure to remove back-home barriers for them. The team rejected the "program police" option. Monitoring or supervising local projects was not part of their agreement with their sponsors, they lacked authority to change local conditions, and, most important, assuming that role would be deeply inconsistent with the way they wanted to work.

- Ignore the disconfirming news and carry on with the training schedule. Participants assigned high marks to the initial sessions and most were enthusiastic. Limits in resources and authority would have made it easy to settle in to a common technical assistance pattern of teaching techniques and concepts in an entertaining way and colluding with participants to blame implementation problems on the system or (absent) others who "don't get it". The team rejected the option of business as usual as inauthentic to their design for the Learning Group.
- Model a process of inquiring more deeply into the situation, surfacing and revising their own assumptions and beliefs about the projects, and adjusting their own behavior and the process of the Learning Group to support each participant to learn what seemed most important to her. This is the path the PLP team chose.

Inquiring into the differences between what they assumed about the local projects and the Learning Group guided the PLP team in reshaping the process of the Learning Group to encourage deeper reflection on the meaning of family support, partnership, and natural support and on the possibilities for creative action. It also stimulated a continuing effort to find words to communicate the PLP team's ways of thinking about these issues.

Assumption

Given their currency and high frequency use in legislation, planning, and previous training, the PLP team assumed that Learning Group members and PLP team members would share a common understanding of concepts central to the local projects. These key terms include: parent-professional partnership; family support; and natural support. While they expected some differences in interpretation and a wide variation in how these concepts would take shape in local circumstances, they assumed that Learning Group participants would be "on the same page."

Discovery

- Participants expressed a variety of different understandings of **partnership**. The PLP team believes that partnership means a person-to-person relationship and a collaboration between equal people with differing gifts and abilities to learn new ways to work. Some Learning Group participants were strongly attached to the system defined roles of "Professional" and "Parent". Some believed that person-to-person relationships were inappropriate either because such a relationship would violate the boundaries of professionalism or compromise the parental advocacy role. This made them uncomfortable with the Learning Group process itself. Some parents experienced their professional partners treating them as clients or as outsiders rather than as colleagues, for example withholding information important to their shared project. Some seemed to reject partnership as a way to learn something new and significant, with some professionals adopting a stance that seemed to say "I learned all I need to know to competently do my job in my professional education" and some parents occasionally taking the counter position that "being a parent makes me the expert."
- Participants expressed a variety of different understandings of **family support**. The PLP team believes that formal services are only one source of family support and that families need assistance to carry their responsibility for finding the spectrum of resources necessary to their family's growth. Some Learning Group participants seemed to understand family support pri-

marily as a service to which families are entitled. Some expected that both the projects and the Learning Group would focus on fixing the deficiencies in the way the local and state service systems behave.

- Participants expressed a variety of different understandings of **natural support**. The PLP team believes that natural support results from active engagement with community people and activities. Building natural support happens as people overcome the barriers to belonging erected by typical responses to disability, so it requires intention and courage and creativity in making personal moves across barriers. Some local projects seemed to understand building natural supports as providing families with information about local human services and helping families deal with problems in accessing services and increasing the ability of service workers to relate respectfully to families. Some seemed to understand building natural supports as informing families about community activities already accessible to children with disabilities. Some seemed to understand building natural supports as increasing local support for human services by increasing referrals or increasing the number of volunteers to human services or increasing contributions or other support to disability organizations and services. Some seemed to understand building natural supports as educating or informing citizens about disability issues and concerns.

Assumption

Because there was a clear case at the state level for putting a priority on building natural supports for families, and because local human service systems volunteered to sponsor projects aimed at increasing natural supports through parent-professional partnerships, and because local areas made a further choice to sponsor a team to participate in the Learning Group, the PLP team assumed that local teams came to the group with sufficient authority and resources to implement a project that local decision makers had designed and approved.

Discovery

- Some teams were not implementing projects designed by local decision makers to build natural supports through parent-professional partnership because such plans had not been locally discussed and adopted as an operational reality.
- Overall, teams encountered so many barriers to project implementation within the human service that it took many of them most of the year to negotiate the agreements and resources necessary to try a project and some teams became discouraged before they had a chance to begin implementing their local project. Teams had far less chance to deal with new sorts barriers to their project's success in their communities than they had obligations to deal with typical barriers to getting things done within the human services.
- While many individuals in local and state systems are concerned about increasing the natural supports available to families, this issue, is only one priority among many competing for their very scare time. In fact, the PLP team, who did not have any administrative role beyond providing the Learning Group, was able to allocate the most time and attention to the projects that the system intended to carry an important responsibility for making change.

Assumption

The PLP team assumed that local team members would have an established and continuing collaboration based at least on their work together in implementing their local project. They also assumed that the management of local human services would highly value the intense training offered through the Learning Group.

Discovery

- Some applicant teams never had consistent professional membership either in local project efforts or in attendance at Learning group sessions.
- Some teams were formed at the initiative of parents interested in participating in the Learning Group. This sometimes resulted in local managers performing "shotgun weddings" between the interested parent and a professional who had time to attend the first session of the Learning Group. Some of these arranged partnerships worked well; others did not.
- Some teams discovered that collaboration with each other was so difficult that their own parent-professional relationship itself posed a barrier to project implementation. Sometimes this had to do with competing time demands, sometimes it was the result of the way parents experienced the professional's treatment of them, sometimes the opportunity for more communication surfaced important differences in values or ideas about key project concepts.
- Some professionals reported that their managers were not prepared to support them allocating the time required for full participation in the Learning Group (six two-day sessions over nine months). Having staff and parents spend extended time in learning did not seem particularly valuable to many local decision makers.

Developing the Process

One way to understand the PLP team's design for the Learning Group is to imagine a set of different lenses for viewing the paths to inclusion. At first, the team structured each session around resource people from whom PLP team members had learned about an important and complementary aspect of building supportive community. Each resource person offered both ways to look at inclusive community and a variety of tools for organizing support among community members. The PLP team believed that each resource person would contribute something of value to the learning group and that different Learning Group members would connect to different resource people based on a match with their diverse personal styles. The team's goal was to have each Learning Group member try on a variety of lenses in order to notice many aspects of natural support. The continuing work of assembling a richer picture of community would provide a foundation for practicing use of the tools resource people had to share.

Resource people were an important part of all but the final Learning Group meeting, but their role shifted as the PLP team took a much stronger responsibility for working together to create a group container for the work

Learning Group members wanted to do. After the second session, the PLP team began to provide strong guidance to resource people about what they should contribute and how the team expected them to work with the group. The PLP team took responsibility for building continuities for the Learning Group by leading rituals, by facilitating dialogue[4] sessions, by organizing exchanges among participants, and by defining the specific ways each PLP team member would contribute to each aspect of each session. Instead of simply acting as arrangers and hosts, the PLP team assumed responsibility for guiding each aspect of the process.

There are at least five reasons for this shift.

- Learning history interviews and participant comments disclosed that many teams were having significant difficulties in partnership with each other. Many of these difficulties seemed to stem from a rigid attachment to the system defined role of "professional" or "parent." This attachment to role seemed to make open, person-to-person communication seem threatening to a number of learning group participants. Not only did restricted person-to-person communication get in the way of people working together on changing their communities, it also permitted superficial responses to what resource people had to offer: "I have already heard this." "I learned this in my professional training." "This is impossible in my situation." "It would be inappropriate for me to behave this way because it would betray my position as a professional or my position as a parent advocate."
- Work to facilitate plans with teams, backed up by the results of learning history interviews, showed how far Learning Group members were from a common understanding of family support, inclusion, and natural community support. Focusing most of the interaction on resource people left the learning group without the necessary space or responsibility to express and explore their own thinking in greater depth.
- While the PLP team felt justified in their belief that resource people had important messages to share, it became clear to them that they were not serving the group with their own considerable skills in facilitating learning. They noticed that some resource people might not know how to structure active involvement and so occupy too much of the group's time in passive listening.

Session-to-Session Continuities That Strengthened the Learning Group

- Developing and repeating rituals
- Practicing dialogue
- Encouraging participants to share resources they have found personally meaningful (stories, books, music, art) as well as exchanging project related information and skills
- Displaying and reviewing key images and displays of important ideas at each session

[4] For a helpful description of dialogue,see Isaacs, W. (1999). *Dialogue: The art of thinking together*. New York: Doubleday Currency.

- A schedule conflict led one of the scheduled resource people to cancel and opened the opportunity for the team to plan a session on partnership relationships in collaboration with the resource person they chose to fill in.
- The PLP team itself experienced struggles about their own collaboration with each other and especially about how to bring new people into work with the team. Looking back at these struggles, it seems possible that the team dealt with its own deference to outside experts in a new way and discovered a more assertive and collaborative way to work with them.

Once the PLP team took active responsibility for guiding Learning Group members to use the skills of dialogue and reflection and the support of shared group rituals to think more deeply, the Learning Group moved into more disclosure of their own understanding of family and community and support and the work of providing services and greater share responsibility for exchange of resources and support with other group members. Some Learning Group members explored questions about the personal meaning of their work, others explored questions about their own marriages and family and community relationships. In these explorations, which explicitly raised the spiritual dimensions of life, distinctions between "parent" and "professional" became less and less relevant and the experience of person-to-person communication became more and more common. Shared car rides and shared meals and hotel rooms became occasions for further exchange and discussion.

Not everyone found this level of thinking comfortable. Some participants expressed increasing enthusiasm for the Learning Group's meetings. Others attended less frequently or held themselves apart from the conversation.

It seems to the PLP team that consciously working to strengthen the Learning Group as a container for serious exploration of personal meanings of family and community increased participant's ability and willingness to look through the different lenses the process offered. As participants spoke their own truths about family and community and service important differences emerged in ways that could be heard better. As differences became more clear, it became possible, from time to time, to glimpse more of the

patterns connecting the differences. Learning group participants began to supplement the lenses offered by visiting resource people with lenses that they were shaping for each other.

Of course, looking through a different lens or hearing a different aspect of the meaning of family and community doesn't necessarily lead directly to visible change. In fact, as some Learning Group members discovered more of the dimensions of what it means to develop naturally supportive community they found themselves in greater conflict with the systems that sponsored their projects or employed them. The Learning Group offered a safe space to seek the lessons in these conflicts.

In a sense, those Learning Group members who participated in the whole process were ready to design a meaningful local project just as the Learning Group was drawing to a close

Reflection discloses a powerful connection between the development of the PLP team itself and the development of the Learning Group. As the team invested in its own development, it dealt with issues of importance to the Learning Group such as the relationship between clients and experts and developing the skills necessary to explore ways of understanding personally important ideas and values when there are important differences.

Sharing in dialogue and reflection with Learning Group participants has helped the PLP team find more words to express their ways of thinking family and community. The next three sections summarize some of that thinking. Reflection on their whole experience with the Learning Group surfaced a more detailed mental model of the effort to engage human service organizations in increasing the natural supports families experience from their communities. The final two sections sketch of this way of thinking about change and describe some of what the PLP team discovered about facilitating the emergence of richer pictures of reality through the creation of a container for learning.

Family Responsibility and the Proper Place of Experts

All children come with gifts essential to community life, and families hold the capacity to identify what is necessary for children to develop and contribute these unique gifts. Families grow stronger when they take responsibility and attract support to deepen their knowledge of themselves and their children and to act on what they know to increase their communities' ability to provide more of the opportunities and resources that all families and children need in order to thrive.

When disability makes a family vulnerable to missing the chance to create good childhood memories with their daughters and sons, families benefit from support to pursue changes in their communities' capacity to include and adapt in response to the difference that disability makes. These changes in communities happen primarily through the creation of reciprocal relationships that allow people to experience the benefits of exchanging support and joining their differing gifts for common purposes.

Relationships grounded in confidence that families have the wisdom to find their way through difficulties to create new possibilities run counter to cultural patterns that raise and reinforce doubt about families' knowledge and prescribe that professionals assume the role of detached experts whose task is to diagnose and remediate child and family deficiencies.

Recognition that all children belong in the same community settings, making use of the same opportunities as other children, runs counter to habits of excluding children and families from ordinary life on the basis of disability, habits which many current service practices perpetuate and justify by separating children in order to serve them. Facing cultural biases toward expert control and segregation can generate fears that tempt people to cynicism about the possibilities for genuine relationships and real partnership for community change.

Honoring families' responsibility to understand and act to get what they need forms the foundation for offering support, information, or technical intervention. Those who provide professional services to families will be ineffective unless they commit themselves to deepening their own gifts of service and supportive relationship. Otherwise, professional influence will inhibit families' discovery and pursuit of their own wisdom. The path to deepening the gifts of service entwines the family path to deepening understanding of and accountability to children's gifts to their communities.

Finding Words

Two Worlds

Families function in two different worlds.

One world is the world of boxes. Boxes order and organize services by deploying...

... program designs that specify objectives and methods and job descriptions

... assessment criteria that determine who enters, transfers among, and leaves programs

... human resource activities that supply staff to meet the program's requirements

... structures and procedures that hold participants and staff accountable to the purposes of the system that authorizes and pays for programs

... budgets that determine how much service will be available and how scarcity will be rationed

Boxes want to be like machines. Boxes divide life into distinct parts, define specific roles and rules for coordination, find ways to screen out uncertainty and minimize risk, and draw clear lines of authority and appeal. Boxes seek uniformity: no matter where one is, no matter who one is, one should be treated the same as any other with similar characteristics. Boxes seek efficiency by training people to fit into their allocated place and to see things in the terms that define the boxes. Boxes analyze human situations into needs that fit linear, step-by-step problem solving methods and monitor their effectiveness by counting things with standardized definitions. Boxes evaluate how well they are doing by checking the conformity of activities to the rules and standards that define them.

When a family seeks prior authorization for a medical service or completes an IFSP or uses the services of a physical therapist or applies for SSI, the family functions in the world of boxes. Among boxes, things will go better for families who know the rules and

procedures and figure out how to use what they know to get what they need from the system of benefits and services.

When a parent joins a board or an advisory committee or task force and influences plans and policies and procedures and budgets, the parent functions in the world of boxes.

The other world is a world of relationships. This is a world of connections and associations, alliances or oppositions, partnerships or competitions. Relationships contain and nourish or frustrate people's attempts to create meaningful lives as they discover and develop their gifts, find where to place their hope and how to decide what is right, and cope with suffering and loss. Relationships organize through the forces of attraction or aversion, agreements honored or broken.

Relationships are like gardens, having their own rhythms. Some relationships last like evergreens, some come and go perennially, some grow and die in a season. Some relationships fill much of a life's space, others a small corner. Relationships can be cultivated, but they cannot be commanded or engineered. Relationships link and entangle and interpenetrate and circle back. Relationships resist exact definition. Relationships flourish or fade depending on the particular, un-countable qualities of their participants. Relationships are a source of risk and a source of resilience, a site for domination and a source of resistance to injustice, a source of hurt and a source of consolation, a source of uncertainty and a site for finding the sense of things.

When a family joins others in observing ritual, celebrates some aspect of shared identity that extends and strengthens its boundaries, associates with others for enjoyment or to pursue a common purpose, or converses deeply with others about what matters to them, the family functions in the world of relationships.

When a parent reaches out to ask for or offer help and to give or receive emotional support and to puzzle over the meaning of a difficult situation, the parent functions in the world of relationship. In the world of relationship, courage to communicate openly, fidelity to live up to one's word, and generosity in exchange increases resourcefulness.

Disability can throw a family out of balance between these two worlds and push them deeper and deeper into the world of boxes. Uncertainty about what is happening and what might help can move parents off their center and into such dependency on the opinions of professionals that they come to see themselves and their child through professional eyes. Instead of being one source of information, the way the boxes see can take over the way the family sees. Rejection and clueless behavior from familiar people and ordinary community members can lead families to make their circle smaller and their walls higher and thicker. The need for assistance, and for ways to cover the continuing costs of assistance, can pull most of a family's energy into negotiating the difficulties that boxes have in reliably delivering relevant help. Working to fix the deficiencies and scarcities that make it hard for boxes to do what's necessary for all the people who deserve assistance can become a career, and so can helping other families to navigate the strange world of boxes. Instead of moving in and out of the world of boxes, some parents find themselves living there almost full time.

Living in the world of boxes deprives families of the resources that flow back and forth in the world of relationships. This isolation and detachment from the world of relationships can turn back on itself, leading the boxes to define disconnection as a need that the world of boxes must fill. But boxes can't satisfy the hunger for friendship and participation. Boxes very fabric and pattern strives to push out and keep out the messiness and the uncertainties and the multiple meanings of the world of relationships. The circles and arcs of the world of relationship can't be encompassed by the straight lines of the world of boxes. The attempt to make the loss of the ebb and flow of reciprocity into a target for professional remediation dooms families and professionals to frustration and confusion.

An all too common service practice makes this difficulty life threatening. In some places, the world of boxes is not a metaphor but a tangible reality. Children with disabilities are transported to physically distinct facilities as a condition of receiving assistance. Professionals expend many dollars and many hours of professional time servicing children in special and separate centers and special and separate classrooms and even special and separate residential facilities. These are not places that children or family

members go for occasional appointments or operations or highly specialized procedures, they are places children go instead of going to the same early education or child care or community recreation settings or schools as their non-disabled brothers and sisters, they can even be buildings children live in instead of living with families. Their parents may be encouraged to volunteer their time in these substitutes for ordinary settings, to raise money to improve the physical conditions of their children's segregation, to serve on boards and committees to uphold civic pride in these boxes as a comprehensive local response to the special and separating needs of these unusual children. At this extreme, more and more of a child's life –even all 24 hours of a day– falls under the logic and rule of the world of boxes.

Finding and keeping a proper and helpful relationship with the world of boxes tests family boundaries and ability to balance.

The Danger of Thinking in Two Columns

Distinctions introduce distortions, though they seem inevitable and helpful to human practice. Analysis allows remarkable discoveries and feats of problem solving. But every time we systematically break the wholeness of life into oppositions, we risk loss of appreciation for the intricate web of connections that expresses and sustains life. The habit of breaking life up into pieces generates social structures that shape our experience and opportunities in ways that are hard to grasp and thus hard to change when they are hurtful and unjust.

For example

In the presence of difference, people think the opposition between "disability" and "normality" into practices of language which bundle characteristics into syndromes and spectrums of disorder and disease, build an industry that manifests the distinction in buildings and budgets and roles and manuals and techniques for assessment and intervention, and then mistake the distinction they have thought for *how things really are*. This last judgement encourages thinking further oppositions between those who "accept" disability/reality and can therefore make sensible statements and those who "deny" disability/reality and need therapeutic adjustment before their voice is worth hearing. Belief in such reality extends a sense of inevitability to the consequences of the distinction. The all-day separation of children from their neighbors for treatment decreases the chances that local schools will confront the issue of adapting to difference and increases the chances that the separated children will lack friends among their neighbors. Under the cloak of disability/reality this slips into the conclusion that disability/reality *necessarily* means that "normal" schools can not educate "disabled" children and that "normal" children will not befriend "disabled" children. The cycle turns again when those who talk of inclusion and friendship

place not just their statements but themselves in the category "unrealistic" from the point of view of those who live uncritically in the world of disability/reality.

One way to expand possibilities turns the process of generating distinctions back on itself, consciously constructing oppositions by reading back from current patterns of experience and practice. These explorations produce stories polarity like those that begin, "Families function in two different worlds" or "People who want to increase natural support through early intervention programs have to live inside the tensions between two conflicting cultures."

These deconstructive stories do their job if they raise awareness of the trail from thinking a distinction to assuming that the distinction and its consequences *are reality*. They do their job if they develop alternative ways to understand and new possibilities for hopeful action. They become at least mildly dangerous if they themselves loose track of their constructed nature and mistake themselves for *the way things really are*, a belief that makes it possible to blame and ignore people who "don't get it," that is, people who don't tell the same story.

Of course conflicts develop between people who act within a dominant sense of *how things really are* and people who have a different understanding that would make a practical difference to the disposition of important resources. Those with a sense of disability/reality will work to expand the numbers for special settings; those with different convictions will work to reduce them and replace them with practices that respond to difference in other ways. In living through these conflicts creatively, it helps if people practice disciplines that encourage them to re-member the wholeness that thought is forever breaking up in order to get things done.

A Richer Picture of the Difficulties of Change

PATH, a planning tool,[5] embodies the underlying approach to change that guided the Learning Group. At the first session, Marsha Forest and Jack Pearpoint, taught the group how to use PATH, and the PLP team modeled the process by creating a PATH for the Learning Group itself. PATH assumes that people who want to make significant change have to find the support and skills they need to hold a creative tension between their sense of a desirable future and their current reality.

The image the PLP team generated to express the future they want to work toward centers on a carousel, a metaphor that celebrates inclusive community life under the slogan "You're Born… You're On." People of diverse colors, sizes, and shapes bearing differing gifts move along multiple paths toward the carousel in time to music from the heart.

- 41 states serve fewer 3 to 21 year old children per 100,000 in separate facilities than Michigan does.
- 34 states serve more 3 to 21 year old children per 100,000 in regular classrooms than Michigan does.
- More than half of Michigan students with multiple disabilities are served in separate facilities.

This image invites learning group participants into a powerful conflict with current reality. From a very young age, many of Michigan's children lose access to the carousel of community life, at least during school hours. The system places almost 11,000 3 to 21 year olds in special, separate facilities and almost 42,000 children in special, separate classes,[6] sinking many dollars and many hours of skilled professional time into settings that directly conflict with the carousel vision. More than 50,000 children live under a banner that says, "You're disabled… You're Off."

[5] Pearpoint, J., O'Brien, J. & Forest, M. (1996). Path (2nd edition). Toronto: ON: Inclusion Press.

[6] Source: *US Department of Education 1998 report to Congress on the implementation of IDEA.*

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This state of current reality goes a long way toward explaining why many families feel isolated. The world of boxes pulls their children out of community life and draws much of their energy into coping with its rules and activities.

Of course, people of good will have differing beliefs about the desirability or the feasibility of inclusion for children with substantial disabilities and no litmus test excluded either parents or professionals from the Learning Group based on their beliefs about inclusion. However, the PLP team vividly drew a space for Learning Group members to explore.

The mission of the local projects made participant's position in this conflict more significant. While it is good to be tolerant of other's individual choices, local projects called on local teams to develop real inclusion through public action. Taking a public stand for inclusion might lead some other parents or professions to feel negatively judged. Failing to regard such a stark conflict between vision and current reality drops the creative tension necessary to motivate change. It is no wonder that the Learning Group continued to search for ethical and effective ways to deal with this conflict.

Living in two cultures

People who want to increase natural support through early intervention programs have to live inside the tensions between two conflicting cultures. These two cultures mirror the two different worlds in which families function: a world defined and organized by boxes and a world of relationship and connection.

It is just about impossible for people who live in the relationship world to avoid knowing about the world of boxes because the world of boxes holds some of the resources they need for their relationships to thrive. However, it is possible to forget what one knows about the relationship world when one works and thinks inside the world of boxes. In the structure of the world of boxes, one earns praise and promotion for thinking and acting like a good bureaucrat-professional or a good parent-service advocate. One's box defines what information one needs to know, what resources one has to work with, and the rules to guide proper behavior. As this happens, the world of boxes drifts farther and farther into its own narrow story about reality, a story in which boxes are all there really is.

Professional experts responsible for defining & managing disability by controlling a range of specialized settings and staff. Family as source of information, client, & helper to professional services	*Beliefs about family, community, disability and the place of experts*	Families hold capacity & responsibility to discover & promote each person's gifts to community. Experts should use their specific competence under family direction. Families & allies work to realize the expectation that all community activities & settings can adapt to include interested people with disabilities.
Respect for definite boundaries between professional & parent roles, clear hierarchy, standardized procedures & techniques lead to efficient use of system resources.	*Ways of thinking about partnership*	Teamwork, based on open & respectful person to person relationships, and alliances based on clearly understood interests form the foundation for hopeful action.
Professionals' role is to determine & assist families to meet their needs for natural support. Natural support is the product of service activities	*Ways of thinking about the meaning & possibilities of natural support*	Families & allies develop reciprocal relationships that include more & more community members in building positive childhood memories & multiplying available social resources
Make rules & regulations Pre-specify, incentivize & monitor outcomes	*Ways of thinking about how to make change in community & systems*	Inviting • Asking • Sharing vision • Persuading • Relying on free choice • Openness to the natural order in what emerges • Minimal attachment to predetermined outcomes
Experts develop & transfer techniques through standard curriculum Experts take responsibility for defining & specifying technical solutions	*Ways of learning*	Go deeper into self through relationship with others. • Acknowledge conflicts & differences • Inquire about (unexpected) results • Look for more connections • Reach out

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This trick of knowledge and forgetting creates a paradox around natural supports that can boggle the world of boxes. Natural support grows in the world of relationships and connections; it can't be reduced to the product of a service system without losing its meaning and its power. Put in a box, natural support loses its supportiveness. Boxes divide and limit people's reach, so many efforts to grow natural support in a box turn from creating opportunities for people with disabilities to pursue reciprocal relationships to generating resources for the service system in the form of volunteer effort, or referrals, or political support for service expansion.

This is not to say that the world of boxes has no role to play in the project of increasing the support families experience from their communities. Human services can transfer money to families rather than controlling the services they must use. Human services can replace services that segregate children with services that assist ordinary community settings to include them. Human services can acknowledge the limits of professional knowledge and refrain from turning people into full time clients. Human services can experiment with less hierarchical forms of organization and encourage service workers to understand their work as assisting rather than replacing ordinary relationships. These moves involve the world of boxes in stepping back, purposely shrinking the amount of space it claims in people's lives, making room for the world of relationships and connections to root and grow.

These moves will only make sense to people who notice that the world of relationships and connections can hold more of what matters to families, including the families' transactions with the world of boxes, than the world of boxes can ever hold. Separation breaks up connection but connections can hold separations.

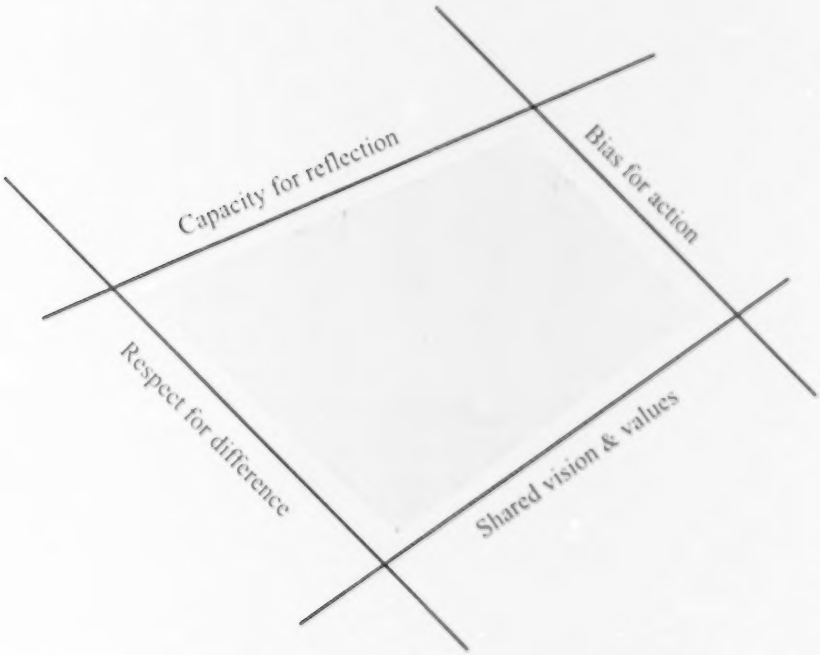
These tensions are sufficiently complex that the Learning Group could only discover them after they learned how work together to create a stronger container to support their puzzling through their diverse thoughts. This process by no means reached conclusion and the ideas here are no more than one more summary of the current state of a continuing conversation.

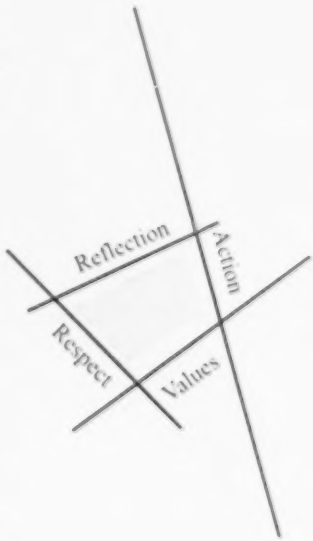
Creating a Container for Learning

Reflecting on the Learning Group from the point of view of the people who participated the most (the PLP team itself), the team can begin to sketch its understanding of what forms the sort of container that allows the kind of learning involved in increasing the natural support available to families.

Like the learning it supports, this container is rooted in the world of relationships and connections. Only a participant who comes to trust the Learning Group will gather the courage to explore the source and meaning of ideas that get harder to understand the more experience she has in working with them.

Four vectors form the container. Vectors with greater length can create a more powerful space for learning if their intersections allow for more of their forces to interact.





Capacity for reflection depends on the Learning Group's willingness to stop doing, or talking compulsively about doing, and making time to be together in a way that opens up space to explore the different ways the group understands a key idea, the conflicts that emerge in action and in finding words and images to understand and guide action, and the patterns that connect at least some of the differences.

Bias for action depends on the willingness of Learning Group members to put new understandings to the test in the world outside the learning group. The group can only go so far in its exploration of asking others to support one's dream unless group members do, in fact ask and experience whatever comes next.

Shared values and vision bind participants together and provide a focus for the Learning Group. The richer shared values and vision become, the more meaningful and useful connections the Learning Group will be able to disclose in action and in reflection.

Respect for difference allows participants to inquire of themselves and others in order to reveal the different ways of thinking at play around key ideas. It allows tolerance for a variety of different contributions to the group's learning –perhaps even extending to a willingness to think about words like these. It grants people permission to suspend their reflexive evaluation and even censorship of what self and others think.

These four vectors emerged unnamed in the learning group as the group experienced more time together, had more shared experiences in sessions and at meals and on rides, built a richer shared understanding through dialogue, and evolved rituals that expressed the spirit of their work together. Now that the PLP team has expanded its skills in facilitating the emergence of such spaces for learning and found names for some of its dimensions and words to express some of what this group learned, their next Learning Group will likely support its participants to move even deeper into the meaning of community, family, and service and into action to create natural supports.